



To whom it may concern:

Please see below for a request for an official proclamation to declare July 30th an annual Gastroschisis Awareness Day in South Carolina. Gastroschisis is a birth defect which causes the intestines to protrude from the abdomen and is rapidly increasing in incidence. It should be noted that Avery's Angels Gastroschisis Foundation, the entity making the request, is based in Raleigh, NC and is the only nonprofit in the entire world specifically for gastroschisis support. Furthermore, July 30th is the date that Avery's Angels founder lost her son (Avery John Rauen) to gastroschisis at UNC hospital at only three months of age. As Avery's Angels Gastroschisis Foundation is working hard not only to support families experiencing gastroschisis but also to fund research to find the cause of this birth defect, a statewide proclamation would greatly help to secure potential investors for this goal. We hope with all sincerity that you will realize how important this observed day will be to South Carolina residents (and ultimately those in other states as well as we hope that in future years, additional governors will grant a proclamation for July 30th in their own states) and declare Gastroschisis Awareness Day on July 30th annually. Thank you so much for your consideration.

Whereas, there are 1 in 2229 individuals born with gastroschisis in the United States, and roughly the same number born in South Carolina annually;

Whereas, this disease may affect small numbers of people, gastroschisis affects many Americans;

Whereas, many Americans living with gastroschisis have serious and debilitating conditions that have a significant impact on the lives of those affected including but not limited to failure to thrive/slow growth, short bowel syndrome, multiple organ transplants, and long term feeding issues;

Whereas, individuals and families affected by gastroschisis often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment;

Whereas, the cause of gastroschisis is relatively unknown, patients and their families must bear a large share of the burden for things such as raising funds for research;

Whereas, hundreds of residents of South Carolina are among those affected by gastroschisis;

Whereas, an official Awareness Day proclamation is often the precursor to funding for research and other avenues of support;

Whereas, Avery's Angels Gastroschisis Foundation (AAGF) is organizing a nationwide observance of Gastroschisis Awareness Day on July 30, 2013, and every year thereafter;

Whereas, South Carolina resident – Kylie Grace Dixon- has slow weight gain and developmental issues due to side effects caused by gastroschisis. She suffers from constipation and has had numerous hospital visits that a 4 year old should not have to endure.

Whereas the founder of Avery's Angels son– Avery John Rauen –passed away from complications of his gastroschisis on July 30, 2009 at UNC hospital, and this date is to commemorate him and all others living with or deceased from gastroschisis;

Therefore, be it resolved that July 30, 2016, will be observed as Gastroschisis Awareness Day in South Carolina, and preferably henceforth in subsequent years.

Sincerely,

Ashley Heath

112 Crossings Blvd. Bluffton, SC 29910

If you do decide to declare July 30th, 2016
as Gastroschisis Awareness Day, our family
would love to present when you declare it.
We do understand though that you have a
very busy schedule. We hope to hear from
you soon. ♡

Sincerely,
Ashley Heath

Contact info:

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May 8th, 2012.

- Day Kylie
was born.



may 14th, 2012.

Kylie had her
closure surgery
to place intestines
back inside.



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